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Abstract (119)

Introduction

The German poet Rilke wrote of breath as an invisible poem (Rilke 1922). The breath is usually literally invisible and it is something we may take for granted until we develop difficulties with it. Then we may begin to feel it is our breathlessness that is invisible to others around us. We may feel silenced. Our life world may shrink (Gysels & Higginson 2010). Those living with breathlessness describe feeling self-conscious, they walk so slowly on the pavement, they hold up strangers and slow down friends. Anxiety levels increase (Leivseth, Linda, Tom IL Nilsen, Xiao-Mei Mai,

Roar Johnsen, and Arnulf Langhammer 2012). Confidence drops (Bailey 2004). Suffering becomes the invisible poem.

In this paper we explore a collaboration between an anthropologist based in Bristol Medical school who is part of the Life of Breath project (www.lifeofbreath.org) and an arts health practitioner who is an expert in the therapeutic use of creative letter writing.

The primary aim of this paper is to explore the stories that emerge when adults living with breathlessness are invited to write a letter to their breath as part of a creative writing workshop. A secondary curiosity is to explore to what extent there is anything universal about the stories we tell when we encounter the breath (and its prolonged or momentary absence) or anything universal about the way fears underlying the breath and our relationship to it are told.

How stories breathe

The sociology of stories debates the temporal sequencing of stories and lived experience. Do stories imitate life or is that “because we have stories, we believe we are having experiences. Experience is, at best the enactment of pre-given stories” (Cheryl Mattingly 1998).

People have experiences - they find they cannot catch their breath when walking up hill or the stairs in their house and then they tell stories that represent those experiences – “how sweet the air is when you don’t have any” (man living with COPD). Or is it that the stories people tell about their breathlessness, are shaped by the cultural and historical narratives in which they are embedded or find themselves situated?

Part of the variation in the experience of breathlessness, how it is expressed and described by those living with breathlessness, is related to the complexity of its perception:

“...[T]he perception of dyspnoea [breathlessness] is a complex individual interpretation process of sensory input that is highly influenced by many nonsensory factors such as attention, emotions, motivation, memory, personality, expectation or prior experience”(von Leupoldt 2007 p.840) .

If the perception of breathlessness is sensitive to emotions, memories and expectations, these in turn cannot help but be touched by stories. In this paper we focus on a specific type of telling – exploring how those living with breathlessness address their breath in letters (as friend, ally or enemy), how they locate themselves within their own illness narratives (whether they locate the problem of their breathlessness as a problem in the air or their body) and how they discover where they are in the story of their breath (are they reconciled with the breath or is their breath and its absence separated from their sense of personhood). In his discussion of illness as a type of “narrative wreckage” Frank (1995) reminds us that “stories have to repair the damage that illness has done to the person’s sense of where she is in life” (p.53). For a person living with breathlessness, a lifeworld shrinks. Places become inaccessible. What were once normal activities, such as showering, getting dressed, walking to the shops, become anxiety provoking. Breathlessness has interrupted a

biographical flow. In this paper, we explore how writing letters to the breath may help someone repair the damage that breathlessness has done to their sense of who they are and how they can live well with chronic breathlessness. Part of this process of repair in the work we report here, was the opportunity to tell their story (as written or depicted in their letter) with the group.

For the Life of Breath project (www.lifeofbreath.org), the need is evident for a greater linguistic, historical and cultural comprehension of the words and stories used to describe and tell the experience of breathlessness. One starting point to meet this need is to explore which narratives emerge when those living with respiratory illness are invited to write a letter to their breath. If stories are “not tools but partners” (Charon 2008), we are also interested in how the letters written to the breath may encourage (and accompany) those living with breathlessness to have a dialogue with their doctors about their experience of breathlessness and how it impacts upon their lives. We were curious whether the stories emerging from the letters to the breath could be the starting point for self-reflection, for example facilitating a shift from feelings of self-blame and stigma towards help-seeking and hope. We were also curious whether any therapeutic value in the process of creating a letter to the breath could impact on the dynamic between patient and clinician. In particular, whether the person living with breathlessness discovers a different way (as a result of the Dear Breath workshop) to tell the story of their symptom of breathlessness when in clinic, a symptom which medicine can do very little to alleviate.

In what follows, we first explore the notion of letters as stories before moving onto discuss our methodological approach in collecting the letters to the breath. We then present the two storylines - stories which explore the boundaries between breath, body, air and personhood; and stories that explore the impermanence of the breath as ‘other’ and entreaties for it to stay. These two narratives are ‘re-told’ in the container of an academic article, relating the narratives to Arthur Frank’s work on ‘narrative equipment’. At the end of the article we consider how future work may relate the stories gathered to ideas within the broader narrative medicine literature. We share visual examples of practice as not all stories about the breath use words as their main story telling “technology” (Ong 1982). Instead the choice of materials becomes an important device for their telling.. In our discussion we conclude by reflecting on the importance of letting stories breathe, in terms of making the lived experience of breathlessness more visible and audible to the general public as well as within patient-clinician relationships.

Letters as stories

The Stanford letter project (<http://med.stanford.edu/letter.html>) is a US based project offering letter templates to empower and support adults to initiate a conversation with doctors and family members about what matters most to them at life’s end. Whilst a successful and much needed project, translated into many languages to increase accessibility, the letter templates are typed up like a form, accessed electronically. The hand crafted aspect of the letter, with its individual and intimate personality, is absent. And with this, a part of the letters capacity to tell an individual story is lost. As far as we are aware, our work is the first to explore letters as stories and explore to what extent therapeutic, hand crafted letters (addressed to an aspect of oneself - in this case the breath) can support communication about breathlessness with family

members and clinicians. Another advocate of using letters as a clinical tool within the clinical relationship is Steinberg (2000). Resonating with our premise that letters are stories, Steinberg suggests the letters written by clinicians to their patients are akin to draft scripts:

“if the therapeutic process is perceived in terms of roles and drama, the letter is like a draft script or ‘treatment’ inviting the comments of the other participants” (p. 119)

In contrast to Steinberg, the work we will share in this article will focus on the workshop participant as the dramatist and the letter to the breath as the script.

Previously we have explored the letter as script and story in terms of its therapeutic value (Penny and Malpass 2019). For Jolly (2011) unsendable letters work because they “perform internal dialogue” (p.48). What we suggest in this article then is that letters written to the breath act as performative texts and dialogues or in terms of creating a stage for the actor ‘breath’ to speak its part. We see an alignment between key characteristics of story (such as character, defining the trouble and plot type) with general tenets of therapeutic process. One thing that links story telling and therapeutic process is the opportunity for (in this case a person writing the story of their breathlessness) to discover what type of narrative (story type) they are currently involved in with their breath -restitution, tragedy of quest (Greenhalgh 2006). Naming the narrative (story type) may help those living with breathlessness think about the story they are telling as well as help liberate them from stories they no longer want to tell, such as stories of self-blame and hopelessness (Frank 2010, p.119). Therapeutic process involves being able to stand back from (the part of us that causes) our suffering and see it differently. It implies, Jolly argues, “the conceptual division of the self” (p.48), the breath as the trouble (as we will present it) is in Jolly’s article the part of us which is “given a personality with its own needs and will” (p.48). The therapeutic process, by no means guaranteed, comes when the letter writer and the breath are reconciled, what Jolly (2011) describes as “a reintegration of the self’s two parts...a self which needs to become conscious of its internal conflicts to bring them into relationship and eventual harmony” (p.48). We have described this previously as a process of reconciling two breath-selves (Penny and Malpass 2019). Creating an epistolary relationship with human breathing allows breathing (and the breath-selves) to be acknowledged, expressed and known in new ways. Our perspective here then views the stories that emerge through creative letter writing as transformative, rather than referential (Greenhalgh 2010). Rather than the letters to the breath being simply reports of what has happened to the person living with breathlessness, how they came to be breathless, the letters potentially affirm, challenge and reframe the narrator’s identity (Frank 2010).

There is a long tradition of novels being written in the form of a series of letters, dating back to the 17th century with Aphra Behn, the first professional woman playwright, publishing *Love Letters Between a Nobleman and his Sister* in 1683. The epistolary novel is composed entirely of letters and has been associated historically with a culturally acceptable form for women writers, because letters were one of the few places for women to either express their creativity or shape their (inner) experience through correspondence. Letters were also socially acceptable in a protestant culture which advocated introspection and conscience searching (Kenyon

1995, p.274). This may be related to why the Stanford Letter project has been so successful, because it places the uncomfortable issue of end of life preferences within a historically familiar form of literary introspection - the letter.

In contrast to novels written in the form of a series of letters, we are looking at individual letters rather than a series of letters and finding the story within that. A future line of enquiry could be inviting participants to write a series of letters to their breath-selves and seeing which other kinds of stories emerge or how this alters the telling of the participant's story through time. There is another thread connecting the discovery of letters as literary form by women in the 17th century and the therapeutic use of letter writing in the 21st century. The thread is to do with power and the therapeutic value of private narrative (Pennebaker and Chang 2011). Those living with illness in the 21st century may choose to disclaim the master narratives of biomedicine and in its place, write their own scripts. The letter is,

“another cognitive space, a less arrogant, less definitive way of inscribing the “I” of the defining (unwell) self “ (Keynon 1995, p.xix, parenthesis added).

The roaming nature of “I” in letters addressed to the (unwell) self is something we explore in terms of character and plot. Letters (to the breath) can be written in the first person, resembling the first person of narrative fiction, or in third person plural, the breath as ‘you’. A starting point for the ‘Dear Breath’ project was a woman living with COPD spontaneously getting out her letter to the breath (created the week before) and reading it out to AM during a cognitive interview (for another project). What was significant for the woman was that she had initially addressed her breath as “you”, then crossed it out and addressed her breath instead as “us”. In this simple action, her whole story type changed, from a tragedy which viewed the breath as ‘antagonist’ and the body as defeated and worn out, to a story in which her and her breath could begin to work together. They were embarking upon a quest.

The story type in letters (to the breath) may be in a realistic or idealising form-the breath cast as a physiological difficulty or a romantic companion who has become absent. As Olga Kenyon in her collection of 800 years of women’s letters suggests, there is much to compare between the letter as a form and the art of creating storylines, defining and resolving trouble and developing character:

“letters deal with significant incidents, with problems and possible resolutions, with responses and conflicts between personalities in ways that link them with pattern-making and character analysis of fiction” (Keynon 1995, p.272)

What we propose here is not only the notion of letters as stories but that the types of stories told in the letters to the breath reveal participants to be at different stages in the process of living through narrative wreckage caused by breathlessness:

“letters have souls, can speak, have in them all that force which expresses the transports of the heart” (P.D. James cited in Keynon 1995, vii)

Research approach - the ‘letter to the breath’ workshops

This was a qualitative study that included participatory observation of the workshops by both authors, recorded group discussion about the letters individuals had created, short qualitative interviews with individual participants and photographs of the letters. A qualitative approach was the most appropriate way to observe and explore with participants the stories which had emerged in their letters and the impact, if any, of the narratives that emerged on their perception of their breath and breathlessness.

We were interested in recruiting three groups: firstly adults already diagnosed with a respiratory condition, experiencing dyspnoea and attending an existing respiratory support group; secondly, adults in the community who were curious about exploring their breath - often because it was a tool in their work; thirdly adults who self-identified as struggling with their breath as a result of a breath related trauma, for example, childhood asthma, panic attacks, sleep apnea. The authors contacted the British Lung Foundation with information about the study who cascaded this to chairs of Breathe Easy Groups in the South West including South Wales. AM collected participants consent forms at the beginning of the workshop after participants had asked questions about the study, including what would happen to any data collected. To recruit from the community, the authors booked rooms in various community based buildings (Quaker halls, Yoga centres, Buddhist centres, workplaces and schools) and advertised through local noticeboards and social media (Eventbrite and Meetup). A detailed account of what each workshop entailed and how we collected and analysed the data are given elsewhere (see Penny and Malpass 2019). Ethical approval for the study was given by the UK based Health Research Authority, the body responsible in the UK for approving research involving patients. The reference number is, 15/EM/0478.

Reflection on methodological approach

The ten workshops have not been about 'writing' stories. Pen use was not encouraged, and ordinary pens not supplied. Participants were invited instead to use brushes, sticks and feathers as well as oils and naturally scented inks (for example, turmeric). The workshops are about *creating visual stories*. In this article then, we take a broad view of what makes a story, to include any type of 'text' where a person relates a story through words, smells and imagery or any combination of these. The creative, visual medium is where anthropologists can meet the 'other' (participant) in the joint activity of play and imagination.—“without turning them (and their experiences) into reified states or static (narratives).” (Hogan and Pink 2010, parenthesis added). Nor should the use of the visual be considered a short-cut to direct communication with an interior world. The letters to the breath should not be considered a form of unmediated access to some interior reality or 'universal collective visual vocabulary' or story. Rather Hogan and Pink (2010) emphasise that the process of making an image is often more important than the finished image. It is the struggle to depict something, the inability to resolve an image, the destruction, overlaying or obscuring of an image that may be a more important part of the narrative than what is actually left behind. As mentioned above, one letter writer first addressed her breath as 'you', crossed this out and replaced it with 'us', enacting in that moment a shift in who was the antagonist in her story.

The route to interiority can also not be linked to the visual sense alone. Hogan and Pink (2010) call for a *multi-sensory methodology*, which is relevant to our work here. When asked about their letters, participants reflect upon the textures of images and the capacity of images to invoke textures, demonstrating the relationship between touching, seeing and story. For those for whom their story about their breathlessness is in some way untellable, our emphasis on creating visual stories is helpful: “the (visual) story traces the edges of a wound that can only be told around...words necessarily fail” (Frank 1995:98). Visual stories are potentially transformative because they may help the person living with chronic breathlessness to explain and understand their experience. The visual stories may highlight unknown and unspeakable fears, providing transformative value. Part of the transformative potential of our methodological approach is that the approach is somatic, not didactic. The suffering of the body is approached through an exploration of the senses and the imagination. As a result the stories which emerge are often visual and performative. But how do formal notions of story manifest in the types of visual stories we are describing? Despite the importance of dialogue in the letters to the breath, for some it is the materials they choose which either tell the story or set the scene to invoke stories about breath in others:

“[the letter looks like] a stage set. With the silver, the curtain just opening, two mountains below, maybe some forests on the left. But it’s just waiting then for the action. Maybe that’s what the breath allows us to do: create a space where the actor can arrive” (M, ND, Workshop 2, Participant 9)

The scene set in this letter, with its views of mountains and tress for the actor breath to arrive suggests a quest narrative. For others, the materials chosen are given character parts to play in the story they want to tell about their breathlessness:

“It’s an Indian or a Chinese scroll, and it’s all rolled up, and you have to uncurl it to read it. And that’s because, if you have asthma, and it’s difficult to breathe, sometimes you feel as though you’re all curled up. But when you open it, inside it has what I think looks like a dandelion clock. And if you have asthma, one of the things that’s good for you is remembering how to breathe and to blow out. So blowing a dandelion clock was always said to be a good exercise. So the dandelion clock helps you to unfurl [like this scroll]. And it’s on a red background and it has the words, “Stay with me,” written in charcoal. You hope that your breath will be easy and that the breath will stay with you, but the charcoal is smudged and that symbolises the days when it’s a bit harder to get breath out. Because, with asthma, it’s actually the breathing out that’s harder than the breathing in. And then you can just fold the scroll up again and start all over again”
(F, asthma, Workshop 3, Participant 12)

Choices of materials align with characters in the story of breathlessness as well as revealing a certain plot. It was important for us to encourage participants to explore visual stories because as Keats (2009) reminds us:

“Visual types of texts are very helpful and useful when participants have difficulty recording emotions, impressions, or aspects that [are] difficult to put

into words. Without a nonverbal means of expression, participants may be limited in how they articulate their experiences” (p. 187)

Our main methodological point is to draw attention to the interface between sensory tellers (letters evoked scent from the various oils and inks available), sensory textures and sights (the choice of materials) and the *telling* of a story.

Findings

Unchosen Stories

Most languages use the same word for breath as they do for spirit, for example in Hebrew the word for *spirit* is *ruach*, which means wind, breath, air, spirit and in Inuit language *anirniq* translates as both soul and breath. Perhaps with the cultural (almost universal) stories and images connecting breath to God or spirit, it is not surprising that the breath (and its absence) is spoken to in these letters as an object of prayer:

“Breath on me, breath of God” (F, ND, Workshop 2, Participant 7)

“I honour you with my presence” (F, ND, Workshop 4, Participant 5)

“You are my saviour!” (M, ND, Workshop 3, Participant 4)

“Thanks for the many moments you have granted and I have taken.
Fortunate, blessed am I” (F, ND, Workshop 3, Participant 12)

The most extreme examples of the breath as an object of worship can be seen in one letter which uses three different colours of ink to write out three different Buddhist chants and mantras - transforming the letter to the breath into an object of ‘devotion’ - a prayer flag (see figure 2)

[insert figure 1 here]

Beyond the tone of homage towards the breath, the story of breath as God given, does little work for those struggling to breathe. In fact none of the examples given above are from those with a diagnosed respiratory illness. Letters written by those with respiratory illness moved beyond this universal historical story of ‘holy breath’ to explore the breath as a set of complex earthly characters. For those diagnosed with a respiratory illness, the story lines of the holy breath had been forsaken. Replaced with an earthly battle for breath.

The trouble and character

Both trouble and character are key defining characteristics of story (Greenhalgh 2006). In our analysis of the letters, we identified a tendency for participants to see their breath as an actor who could play different characters with different parts, as seen in the following examples from letters. Breath as memory keeper - “do you remember when?”; Breath as soother - “keep me calm and sane”; Breath as support - “focusing on you helped me cope...steadied me”; Breath as teacher - “the lesson has been a long one, soothe us, steady us, teach us something about life about ‘letting go’”. When the breath was cast as a lover or parent, the narrative was about the nature of the relationship:

“I am very pleased we are getting to know each other better and to enjoy each others’ company now that we have reached an understanding”
(F, COPD, Workshop 1, Participant 12)

‘Reaching an understanding’ suggests the letter writer has not always been able to enjoy the breath’s company. The idea of ‘trouble’ as integral to any storyline causes Frank (2010) to describe it as the first piece of narrative equipment a story teller grabs onto: “something goes awry, otherwise there is nothing to tell about” (Frank, p.28). Some letter writers were more explicit about the extent of difficulty or trouble in their relationship with the breath:

“I have lived with you for 83 years, the first 23 years were good, but you have been unkind for the past 60 years, starting with the birth of my son. Why? Is there a reason for this? I’ve forgiven you as I have survived though it has been a struggle. The struggle now continues through my son and his breath.”
(F, COPD, Workshop 1, Participant 8)

The above letter writer demands to know why the breath has behaved as it has. The breath is given agency in these letters and asked to justify its combative nature. The breath is addressed as an ‘other’ with whom the letter writer must contend. Often the breath is addressed as one who has deserted the letter writer, torturing through absence. This was true for workshops held with Breathe Easy groups;

“most of the time I love you and value you, sometimes I can’t find you when you make me cough, but I need you to stay with me just as long as you can”
(F, COPD, Workshop 1, Participant 5)

As well as in workshops with those who use the breath in their work:

“and then you were gone. Scratched out, written over. Erased. We forget you’re there. Then you remind me with your sucked away fading. Too fast. Not enough.”
(F, panic attacks, Workshop 2, Participant 3)

For some, the materials were chosen to deliberately depict an aspect of the breath’s character, as a traveller who is worn and used:

“I got a bit of cardboard and ripped it at the edges so it was not regular, it looked used and worn, as my breath is used and worn” (M, ND, workshop 3, Participant 5)

The breath was addressed in the letters as someone who can betray us, who is capable of being unkind and needs our forgiveness:

“you have been unkind...why? Is there a reason for this? I’ve forgiven you”
(F, COPD, Workshop 1, Participant 3)

All the above examples demonstrate how letters create characters with a capacity to display and test people. These stories of the breath cast both breath and the self as separate characters who must both “exert efforts to come to terms with whatever the trouble is. The stories tell the success or failure of those efforts” (Frank 2010, p.29). The work of stories is to teach listeners (and authors) how to regard themselves

through the interplay of characters (Frank 2010). In the case of breath, we have seen this played out as abandoned or jilted lover, or as we shall see, as hopeful and grateful companion.

Suspense

For Cheryl Mattingly (2000) ideas of suspense revolves around the inherent tension between what we fear and what we long for, linking the power of stories to their capacity to remind us of the fragility of events.

Suspense in the letters sometimes took the form of addressing the breath as life giver, the uncertainty that surrounds one's mortality and the role breath plays in determining life:

“thanks for my life and keeping me alive”

(F, ND, Workshop 5, Participant 5)

For some the uncertainty and ambivalence towards the ‘holy breath’ was linked to suicidal ideation:

“You give me life. But is that what I want? But is that what I want?”

(F, ND, Workshop 5, Participant 7)

For letter writers the suspense of continually living with the uncertainty of breathlessness would regularly reach a climax:

“Limiting. Can't work as hard as before. Gasping for breath. Short of breath. O₂ goes low. Heart and brain lack of oxygen. Dangerous!!! Organs don't work as well as they should” (M, COPD, Workshop 6, Participant 11)

In the example above, the narrative is written in short gasped sentences, the writing style mirroring the narrative being described.

The staccato pacing of words has been equated with chaos narratives, presupposing a lack of control (Frank 1995). Other letter writers explored suspense in more conversational tones, in terms of their bodies' asthmatic tendencies not to let go of the breath, creating physical tension and emotional strain:

“Dear Breath. Let go. Just let it go please. There is no need to cling on. You have been there for me through the toughest times. With me. In and out of me. Around and over me. But we are holding on to something. It is time to ease out of it, out of the body. Something crushing. Something stuck. You make my head spin. Where are you? Where do you disappear to? I can trust you to come back can't I?”

(F, asthma, Workshop 7, Participant 1)

Gooch (1995) suggests that in good script writing, dialogue should be the last thing a character does, not the first. And only because it's absolutely necessary. It should be almost as if the lines were forced out – from sheer necessity, that there is such an urgency in the situation, in the point of conflict between the characters, that speech is the only solution. Only when the situation is speaking urgently to them, do characters really need to reply. The way we set up workshops in this project, by preparing participants with warm ups which explore their sensory experiences of

their own breath, does mean that dialogue may be the last thing a letter writer participant uses. We encourage a wide personal choice of materials and we make clear that images are good ways to express what participants may want to say. The use of feathers and sticks in the writing slows down what the participants write. When words are actually used they may well be expressing what nothing else can. Sometimes it may be the chaotic last chance to express what a participant needs to say.

We have explored elsewhere (Penny and Malpass 2019) that the letters reveal a range of styles and types of dialogue between the protagonist (self) and antagonist (breath), ranging from argumentative:

“I wonder what you get up to when I’m asleep, because I don’t know. What do you get up to? Ok fine don’t tell me”. (M, ND, Workshop 8, Participant 2)

To beseeching,

“flow, don’t be afraid”. (M, ND, Workshop 4, Participant 7)

Reconciliatory,

“dearest breath, breath me always”. (F, ND, Workshop 4, Participant 9)

And thankful:

“thank you for calming me down when I start to panic I appreciate everything, lots of love”. (F, ND, Workshop 5, Participant 2)

For some letter writers, suspense was about empowering the breath with the ability to bring about freedom:

“Untangle me from my web of thoughts. Set me free” (F, ND, Workshop 8, Participant 10).

Echoing the earlier personification of the breath as lover or parent, suspense was often about feeling conflicted in relation to the ‘other’, a desire to be released, set free versus a desire to be brought in close:

“Release me, draw me into you” (M, ND, Workshop 8, Participant 6)

Reaching a Resolution?

We were interested to see to what extent the letter writing facilitated a resolution of the suspense. Did the letter writer and their breath make friends, or agree to disagree or fall out once and for all? The most common re-occurring theme was an entreaty for the breath to stay, to not abandon the letter writer:

“I would like you to stay with me all the summer and together we shall enjoy the garden and walking in the woods - if you can manage to stay happily that long.”
(F, COPD, Workshop 1, Participant 7)

The narrative of entreaty was sometimes said in just a few words:

“Stay with me” (F, COPD, Workshop 6, Participant 2)

“Stay with me just as long as you can” (F, COPD, Workshop 1, Participant 4)

“Don’t leave me, please” (F, ND, Workshop 5, Participant 3))

[insert figures 2 and 3 here]

And sometimes the narrative of entreaty was filled with great love, conviction and hope:

“I’m here for you, I’ll catch you” (F, ND, Workshop 4, Participant 8)

“Kisses. Sharing breath. Soul to soul. Not alone” (M, asthma, Workshop 2, Participant 3)

Most entreaty narratives emerging in the letters involved confronting the breath and offering words of reconciliation:

“I’ve chosen this pretty paper to remind us what my life and being used to be like. Sadly my reaction to your affect (sic) on me since our illness has made me into a sad, grumpy, worn out woman. Medication is helping to keep us going but how I wish you and I could feel happy for more than we do. Remember that sweet little girl we were? Couldn’t we work together to be a happy, positive body? How can we do that?”
(F, COPD, Workshop 1, Participant 2)

In some of the letters, we see the narrative of reconciliation being told in terms of a joint struggle:

“sorry you have to struggle with your lungs but I’m struggling too. I take medication to help us both” (M, COPD, Workshop 1, Participant 4)

“I wish I could make it easier for you, I can’t, but together we will battle on”
(M, COPD, Workshop 1, Participant 6)

Reconciliation as a narrative was not an expected or inevitable stage of the workshop. Not all participants were ready to engage with their breath in this way and narratives of reconciliation could be meaningless for some. For some, the workshop was an important opportunity to simply meet the breath as a character and discover where they were in their own story. Approaching breath as a character or an event involving a plotline permits the letter writer to view the breath as external to the individual, as something (or someone) with a life of even death of its own, allowing for the expression of personal dependency, anxiety, anger, fear, relief, struggle, uncertainty and isolation.

Frank (1995) names three types of narrative: restitution, chaos and quest. We may have expected chaos narratives to dominate, as the letter writer experiencing chronic breathlessness has a “body imprisoned in the frustrated needs of the moment” (Frank 1985, p. 98). Instead, in the narratives of resolution described above we can see threads of the quest narrative, attempts to frame breathlessness as a challenge

to be overcome. We can read tones of love and faithfulness towards the breath-self: the letter writer is willing and ready to 'catch their breath', 'work together' and 'battle on' united as 'we'.

Stories of air and struggle

The stories the letters to the breath tell us about the relationship of the air to the body provide some interesting narratives of how breathlessness, air and bodily knowing fit together. For example, the narrative cited below names various body parts as characters in addition to 'the Breath': Lung and Brain. The characters must "all work together" and the letter writer gives the character Lungs some moral support and encouragement in the narrative:

"Breath. Lungs. I realise lungs that you can do it. You do not need to gasp all the breath every time you get an allergic reaction. Allow the brain to do its job of balance. The body is made of many parts so all work together. *Breathe out excess gases to allow room for the young fresh air.* All the other parts of the body value your effort knowing you do try. We are behind you with this." (F, allergies, Workshop 9, Participant 2)

The 'young fresh air' is also a character here but air's youth, in contrast to the worn and old lungs, is given less agency. The letter writer is imploring the Lungs, on behalf of the rest of her body parts, to "allow room" for 'young fresh air' to enter the scene. This narrative resonates with Megan Wainwrights (2017) work in Uruguay on breathless sensation, amongst those living with COPD, as environmental embodiment. She writes,

"breathing and air are intimately entangled, in that sensing the breath inside the body is sensing the air outside it. We exhale part of our body into the world and we inhale the environment into our bodies" (p.342).

It is Wainwright argues, not only our eyes, ears, noses and our taste buds which connect our inside bodies to the outside world but also our lungs.

Instead of breath or body organs being the character in the narrative, participants sometimes wrote about the air as the main character. Their letters explored the relationship between the characters of body, breath and air, within the ideas of there being a moral atmosphere in which there exists 'good and bad air'. The question that arose for us was 'does framing breathlessness in terms of a struggle with air, as opposed to a struggle with the lungs or even a struggle with the breath tell us something important about how people perceive breathlessness and its causes?

In our attempt to answer this question, we considered that in the literature of respiratory illness a large burden of the stigma surrounding COPD is its association with smoking. Even if patients have not smoked themselves and their COPD is linked to occupational exposure (for example chefs or engineers), the mere association of COPD with smoking can cause a felt sense of stigma. Those with COPD who were smokers report feeling guilty about taking up clinicians time when

they have ‘brought their disease upon themselves’ (Halding 2011). Yet the recent 2017 ‘Global Air Report’ (State of Global Air 2017 Report) shifts some of this disease burden away from the individual self onto society, highlighting the health impacts of air pollution, with the report suggesting up to 27% of COPD deaths can be linked to air pollution. The self-blame cultures of respiratory illness are beginning to be replaced slowly in the public domain with headlines about air quality. When writing a letter to their breath, the breath-self is being formed in what is written or created, by adapting storylines that cultures make available. So how do letter writers tell the story of the relationship between air, breath and struggle?

In one letter, the story of the breath as air, is told in three parts, - (see figure 5)

“3 steps to one breath.

Air I breath in

Air I have used

Air that is expelled” (M, COPD, Workshop 3, Participant 5)

[insert figure 4 here]

There are some interesting things to note about how the visual aspects of the story give us insight into how the character of breath is created. The pronoun ‘I’ is not used in the description of the exhale, just in relation to the inhale. This helps the letter writer to depict the air we expel as no longer being identified with the self, as ‘mine’ but is something given back to the world. The small grey coloured puffs of air, smoke like, held in each heart or balloon shaped alveoli, create a speech bubble. The alveoli interact with the cloudy grey air below shown through the smudge of grey charcoal across the paper. The smudge resonates with how this person described his breath, as misty and hazy and relates to the stories told amongst the group about being exposed to air pollution which many traced back to their current causes of their breathing difficulty. For example, in picture 6, the cotton wool has been used to tell the story of her memory of walking through London smog as a 15 year old, holding a torch in front of a bus to warn oncoming traffic. Her clothes were black when she got home:

“: Because, many years ago, walking along in the smog, because I was a Londoner, and it was extra bad, especially when they had the strike, and we had to walk all the way home, which was a good five miles. Holding up a torch in front of the bus. Yes, very nasty. You got home and you was black all over...Yes, so at the time, I was only 15, you don’t realise the damage it’s doing, and it’s going into you and you’re struggling now” (F, bronchiectasis, participant 4, workshop 9)

[insert figure 5 here]

And yet her letter simply says ‘this is me struggling to breath’. The story of the air pollution is only told when describing her picture, it remains a hidden transcript (Scott

1990). In these two storylines about the air, there is shame and an uncomfortable relationship with both being a polluter and being a victim of pollution. In contrast to this polluted and often shameful relationship to the air, those using breath in their work focus on the interconnected nature of breath, air, self and other:

“Breath oh breath. Paper thin, one thread connecting my life from first breath to last. Traveller through time and space, I sip the air. AIR. BREATH” (F, ND, Workshop 4, Participant 2)

Images of sipping the air, which is fragrant and sweet, contrast with the earlier images of “struggling to breathe” .

In contrast to our earlier discussions of ‘holy breath’ we see in these stories a confessional and apologetic tone, with letter writers apologising for poisoning the air they breathe:

“expel the toxins I have poisoned you with. Forgive my failings and help me to nourish you” (M, ND, Workshop 3, participant 5)

There is a return, almost, to the homage we noted earlier. Asking for forgiveness for having sullied the God given breath, the holy breath:

“the air is pure, my body weak” (F, COPD, Workshop 9, participant 3)

“air is beautiful and I make it bad” (M, COPD, Workshop 6, participant 7)

For those living with respiratory illness, the tone of the story is without redemption, the breather made the beautiful air ‘bad’. He cannot be forgiven in this story. Whereas Frank (1995) offers just three types of narrative (restitution, chaos and quest) what we see occurring here is a fourth type of narrative: *retribution*. A narrative of blame, framed very much in the shadow of ideas of ‘holy breath’, so that a man struggling to breathe feels compelled to tell his story as one in which he makes the holy air ‘bad’.

Yet not everyone chose a retribution narrative. For one participant, she consciously used the workshop as an opportunity to meet another in her cast of breath selves - she chose to meet an aspiration breath-self. This woman wrote to her breath:

“Dear Breath of my Life, I depend on you but sometimes I forget that. I promise to spend more time loving and nourishing you.” (F, ND, Workshop 9, Participant 3)

What is interesting is when later reflecting on her letter, she confides another narrative she chose to put to one side:

“Participant: because I’m actually a smoker. And I fight with that a lot of the [laughs] time with myself. I give myself a hard time over it. And I have been, I was off them and now I’ve come back on them...And I know I shouldn’t be smoking because it does affect my breath and I can feel the difference in my breath. And I watched my grandmother die from cigarette smoking, and so I watched her take her last breath.... So there’s a lot of internal conflict going on at the moment. But I’m also kind of moving away from them again, so it’s good.

AM: So there’s no shadow. Because sometimes in these letters we see people use a lot of charcoal and dark shadow. There’s nothing like that in here. It’s a very light image.

Participant: But that's what I wanted to focus on. Because initially I was going to, "I'll draw a cigarette and put a big X across it. I'll put like, I'll put shadows on that, so that'll be shadows on the lungs." And then I thought, "No, I focus on that too much." And actually it's time to focus on this (aspiration to practice more yoga and connect to the holy breath)– it's a shifting in the perception" (F, ND, Workshop 8, Participant 3)

We see here reflections on the quest narrative at work, in which the letter writer discovers not someone new, but someone she has been and wants to become again.

Discussion

Re-telling stories

Despite the narrative turn in medicine, its advocates within medicine such as Trisha Greenhalgh (2006, 2017) continue to report how many illness narratives remain unheard, with "many more failing to illuminate, inform, heal or transform the experience they describe" (p.14). When we offer participants the opportunity to take part in a workshop we are offering a space for participants to explore the kind of relationship they have with their breath and a chance to tell their story. One of the important parts of the workshops, especially for groups with a respiratory diagnosis, was the sharing of the letters at the end of the workshop. This was, for some, the first time they had talked about how their breathlessness made them feel. The story teller, Pleasant deSpain reminds us never to undermine the power of sharing words:

"When my listeners and I share the same breath, inhaling and exhaling simultaneously as the story unfolds, human bonding occurs. We feel not only more alive with imagination, emotion and expectation but more together in our shared humanity" (www.pleasant-despain.com)

As well as creating a sense of shared narrative, the workshops are also helping to create a *public* story, raising awareness about breathlessness, going some way to make breathlessness and its storylines more visible

In a collaboration with a visual installation artist we have developed the letters into a visual art installation (see pictures 8 and 9). Louise Jenkins described her intentions for the piece:

"I arrived at the idea of making containers of breath out of the letters. The invisible breath held as a solid form, with the form expressing the energy created by the individual's breath (or lack of). Suspending the breath within a glass display dome references the clinical gaze, and *brings the viewers attention to the isolation and the individual whose story is held within* – creating a physical presence of the breath and a visible experience of the creators." (personal correspondence)

It is interesting for us as researchers and arts in health practitioners to note that Jenkins wanted to communicate the isolation of the "story held within". Liberating the story and allowing the stories of breathlessness to breathe so that they can speak in the public and clinical domain is one of the objectives of Life of Breath's work. We

should never underestimate the power of stories, as Frank reminds us “stories are made of air but leave their mark” (p.43).

[insert figures 6 and 7 here]

Telling stories about the experience of breathlessness has power in part because *the story has breath* – the story comes into the public domain to teach those who do not know what it is like to be breathless. Our letter to the breath project is about encouraging patients to have a dialogue with themselves, to discover where they are in the story with their breath and discover what it is they need to teach their clinicians. As the clinicians Currow and Johnson (2015) discuss that there is still a long way to go before clinicians routinely stop “reducing the experience of breathlessness to a unidimensional clinical sign like ‘Peak Expiratory flow’ or ‘respiratory rate’” (p. 1527). As we develop this work and explore ways to integrate it into primary and secondary care service settings we also see the workshops supporting patients to have a dialogue with their doctors about their breathlessness and its impact on their quality of life. We would like to take what we have learnt from the stories that emerge in creative letter writing workshops into healthcare settings. This may involve relating to the stories in terms of treatment narratives and encouraging patients to locate themselves within their own *treatment narratives* - how they treat themselves and they are treated by their doctors. Letter to the breath is one potential direction for developing what Rita Charon (2007, 2008) describes as ‘narrative medicine’ but within the context of breathlessness and from the perspective of patients.

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